Embracing Change with All Four Arms:
A Post-Humanist Defense of Genetic Engineering

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Abstract

This paper sets out to defend human genetic engineering with a new bioethical approach, post-humanism, combined with a radical democratic political framework. Arguments for the restriction of human genetic engineering, and specifically germ-line enhancement, are reviewed. Arguments are divided into those which are fundamental matters of faith, or "bio-Luddite" arguments, and those which can be addressed through public policy, or "gene-angst" arguments.

The four bio-Luddite concerns addressed are: Medicine Makes People Sick; There are Sacred Limits of the Natural Order; Technologies Always Serve Ruling Interests; The Genome is Too Complicated to Engineer. I argue that these are matters of faith that one either accepts or rejects, and that I reject.

The non-fundamentalist or pragmatic concerns I discuss are: Fascist Applications; The Value of Genetic Diversity; The Geneticization of Life; Genetic Discrimination and Confidentiality; Systematically Bad Decisions by Parents; Discrimination Against the Disabled; Unequal Access; The Decline of Social Solidarity. I conclude that all these concerns can be adequately addressed through a proactive regulative framework administered by a liberal democratic state. Therefore, even germ-line genetic enhancement should eventually made available since the potential benefits greatly outweigh the potential risks.

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1. Introduction

Nine years ago Jeremy Rifkin convinced me that genetic technology would determine the shape of the future while I rode a bus through the small, crooked, immaculate and beautiful streets of Kyoto. I was reading his *Algeny* [Rifkin, 1983), an alarmist attack on the coming of the gene age, alongside *What Sort of People Should There Be?* [Glover, 1984), a moderate defense of genetic engineering by the Oxford don Jonathan Glover. In a sense, in the nine years since, I have recoiled from the radical Rifkin to embrace the reformist Glover.

In earlier decades Rifkin had been an SDS activist and a founding member of the socialist New American Movement. Sometime in the early 80s, Rifkin saw the distant headlight of gene-technology and began to sound the alarm. Since then Rifkin and his Foundation on Economic Trends have led the fight against the release of genetically engineered organisms and the funding of genetics research, as well as other "trends" that Rifkin is worried about, such as the meat industry [Rifkin, 1992), the legal establishment of surrogate motherhood, and the speeding up of experienced time in the computer age [Rifkin, 1987).

While extreme, Rifkin is a bellwether of Luddite tendencies in bioethics and the political Left, two of the movements within which I construct my worldview. Among bioethicists the anti-technological agenda has focused on abuses and social dangers in medical research and practice, and our alleged need to accept death and technological limits. The post-60s, environmentalist Left focuses on the ways that technology serves patriarchy, racism, imperialism, corporate profits, structural unemployment, the authoritarian state, and domination by scientific discourse. The response of bioethicists [Lappé, 1972, 1987; Kass, 1972, 1973, 1979; Ramsey, 1970. 1972, 1978; Duster, 1990; Council for Responsible Genetics on Human Germ-Line Manipulation, 1992) and the Left [Keller, 1991; Heins, 1991; Morales, 1991; Klein, 1991; Miringoff, 1991; and Hubbard and Wald, 1993a, 1993b) to genetic engineering has been particularly fevered, driven by accusations of eugenics and the defilement of sacred boundaries.

Since that bus ride in Kyoto my initial horrified agreement with Rifkin has shifted to determined agreement with Glover, that we can control genetic technology and make it a boon rather than a bane. Instead of a *Brave New World*, I see genetic engineering offering a grand, albeit somewhat unpredictable, future. While many of the concerns of ethicists and the Left about this technology are well-founded, I now believe they are answerable. While I still acknowledge the need for democratic control and social limits, I am now convinced that banning genetic engineering would be a profound mistake.

Those who set aside angst about changing human nature, and embrace the possibility of rapid diversification of types of life, are establishing a new moral and political

philosophy for the 21st century, a system some refer to as "post-humanism." The term “post-humanism” was coined by cyberpunk theorist Bruce Sterling in his 1985 novel *Schismatrix*, and popularized by a loose network of anarchocapitalist technology enthusiasts who refer to themselves as "extropians" [More, 1990, 1992, 1994). On the Left, the principal touchpoint for post-humanism has been Donna Haraway, starting with her delphic 1985 "Manifesto for Cyborgs."

Like all philosophical systems, post-humanism incorporates prior philosophic and political systems but recasts them around new definitions of personhood, citizenship, and the limits of social solidarity and human knowledge. Like Glover, post-humanists view the coming of genetic technology the way most Americans now view organ transplants or chemotherapy; there are many practical questions about how the technologies get developed and tested, who needs them, and how we pay for them, but there is no question that they should be available.

Unfortunately most post-humanists are unalloyed libertarians and anarchists, and offer no answers to concerns about the way that social inequality will shape, and beshaped by, genetic technology. In this essay I will be trying to imagine what our current liberal democratic societies could be like if we allowed a post-humanist flowering of genetic technology, and how many of the alleged problems of genetic engineering can be addressed through radicalizing both democracy and liberty, rather than by erasing the State or imposing Luddite bans.

2. Distinctions without a Difference

Many writers on these technologies draw distinctions between "negative" and "positive" genetic modification, and the modification of the somatic versus germ-line cells [Glover, 1984; Krimsky, 1990; Moseley, 1991; Elias and Annas, 1992; UNESCO International Bioethics Committee, 1995). Negative genetic modification has been defined as the correction of a genetic disease, while positive modification has been defined as the attempt to enhance human ability beyond its normal limits. The somatic-germ-line distinction has been made to address the alleged ethical difference in modifying only one's own body, versus modifying one's progeny as well.

Both distinctions have been made by those who wanted to draw a line to demarcate the ethical boundaries of genetic research. The distinctions are quite fuzzy, however [Krimsky, 1990; Bonnicksen, 1994A). Take for instance Culver and Gert's effort to define "malady" to distinguish when a genetic therapy is or isn't "enhancement":

> A person has a malady if and only if he has a condition, other than his rational beliefs and desires, such that he is suffering, or at increased risk of suffering, an evil (death, pain, disability, loss of freedom or opportunity or loss of pleasure) in the absence of distinct sustaining cause. [Culver and Gert, 1982: 125)

Doesn't any cause of illness, suffering and death, or inadequacy in the face of one's goals, fit this criteria? Take for instance a potential future genetic therapy that turned off a hypothetical aging switch, doubling the human life span; is this therapy for the diseases

which result from the activation of the aging switch, such as Alzheimer's or cancer, or an unconscionable intervention into the natural span of life?

As to the modification of one's own genes versus future progeny, the argument is made that current generations would be violating the self-determination of future generations by doing so. The first response is that our choice of breeding partners already "determines" the biology of future generations. Take the case of a couple who both carry a gene for latent inheritable mental illness. The only difference between their choosing not to breed with one another, and choosing to have germ-line therapy on themselves or their child to correct the illness, is that the latter choice is a far happier one.

Technology itself makes the distinction unhelpful, since some viral vectors will introduce DNA into both somatic and germ-line cells, and some disorders will require intervention at the blastula stage or before conception in order to be effectively treated. Genetic technology will make it possible for future generations to change their genes back if they don't like them. Only modifications which remove decision-making autonomy from future generations altogether would truly raise issues of "self-determination," and I will discuss such fascist scenarios below.

These distinctions are extremely fuzzy, and do not represent important *ethical* boundaries. In this essay I want to defend genetic therapy *and* enhancement, as well as self-modification by competent adults *and* our modification of our progeny. Most international consensus statements have drawn the line at germ-line therapy, or genetic enhancement, or at least germ-line enhancement [Bonnicksen, 1994A) although language about these matters are conspicuously absent in two recent statements [UNESCO International Bioethics Committee, 1995; HUGO, 1995).

Therefore, the center of the terrain that I want to defend is germ-line enhancement, the modification of the genetic code such that the parent passes on the enhancements to their progeny. The defense of this practice necessarily addresses the concerns about many other technologies, such as:

In-Vitro Fertilization
Surrogate Mothering
Extra-uterine Gestation
Genetic Screening and Diagnosis
Genetic Selection, including Sex Selection
Cloning of Embryos

In a more fundamental sense I am writing in defense of our control of our bodies, individually and collectively. I want to build a broad enough defense to cover any technology offering modification of human abilities, whether a specific genetic application has been imagined for that purpose or not.

3. Ethical Starting Points for A Defense

A. Rule Utilitarianism

In general I assume the ethical stance of Millsian rule utilitarianism: acts are ethical which lead to the greatest good or happiness for the greatest number. *Rule* utilitarianism means that, when confronted with a distasteful case, such as throwing a Christian to a lion for the amusement of thousands of Romans, I fall back on general rules of thumb: "In general, societies that respect individual rights and liberties will lead to greater happiness for all."

In the case of genetic engineering my broad assertion is that gene-technologies can, and probably will, give people longer, healthier lives, with more choices and greater happiness. In fact, these technologies offer the possibility that we will be able to experience utilities greater and more intense than those on our current mental pallet. Genetic technology will bring advances in pharmaceuticals and the therapeutic treatment of disease, ameliorating many illnesses and forms of suffering. Somewhat further in the future, our sense organs themselves may be re-engineered to allow us to perceive greater ranges of light and sound, our bodies re-engineered to permit us to engage in more strenuous activities, and our minds re-engineered to permit us to think more profound and intense thoughts. If utility is an ethical goal, direct control of our body and mind, through genetic control, cybernetics, prosthetics, or whatever, suggests the possibility of unlimited utility, and thus an immeasurable good.

B. Privacy, Self-Determination and Bodily Autonomy

But there are other rules to consider, rules which are the basis of other ethical systems. Most utilitarians, and many others, accept the general rule that liberal societies, which allow maximum self-determination, will maximize social utility. The rule of, or right to, self-determination also argues that society should have very good reasons before interfering with competent adults applying genetic technology to themselves and their property. Self-determining people should be allowed the privacy to do what they want to with their bodies, and the conceptive products of their bodies, except when they are not competent, or their actions will cause great harm to others. I will argue that most concerns about human genetic engineering do not amount to a clear and present danger to the public safety adequate to legitimate violating bodily autonomy and personal liberty. My objection to state intervention in personal liberty holds especially true for moral appeals to defend “human nature,” “public morality,” and so on, such as the language of many consensus statements which argue against genetic technology alleging defense of “human dignity.”

Acknowledging self-determination as an ethical starting point addresses half of the revulsion to genetic engineering: the concern that people will be forced to conform to eugenic policies. I will discuss this fear of racist and authoritarian regimes at greater length, but suffice it to say here that individuals should not be forced to have or abort children, or forced to modify their own or their children's genetic code. I heartily endorse the formulation of the Preliminary Draft of a Universal Declaration on the Human

Genome and Human Rights [UNESCO International Bioethics Committee, 1995) which states that

> 7. No intervention affecting an individual's genome may be undertaken, whether for scientific, therapeutic or diagnostic purposes, ... without prior, free and informed consent of the person concerned or, where appropriate, of his or her duly authorized representatives, guided by the person's best interests.

In this essay, I am articulating the genetics policies that liberal and democratic societies should adopt; I am opposed to racism and authoritarianism, and any racist or authoritarian application of genetic technology.

I also view the embryo and fetus as the biological property of the parents, and exclusively of the mother when *in utero*. Again, the rights of the future child and of society may restrict what we allow parents to do to their prenatal property. But I would again argue that the risks to society and to the children themselves of prenatal genetic manipulation are negligible for the near future, and regulable as they become apparent.

C. Freedom from Biological Necessity

Genetic technology promises freedom and self-determination at an even more basic level: freedom from biological necessity. Social domination pales before our domination by the inevitability of birth, illness, aging and death, burdens that genetic technology offers to ameliorate. As for Marx, the goal of this revolution is to move from the realm of necessity to the realm of freedom. Just like industrial automation, genetic technology is a technology with liberatory possibilities; the difficulties lie not in the means of production, but in the relations of production, the social and political context in which the technology is deployed.

A second, and far less Marxian observation, is that social domination has some biological determinants. Patriarchy is, in part, based on women's physical vulnerability, and their special role in reproduction. While industrialization, contraception and the liberal democratic state may have removed the bulk of patriarchy's weight, genetic technology offers to remove the rest. Similarly, while racism, ageism, heterosexism, and so on may be only 10% biological and 90% social construction, at least the biological factors can be made a matter of choice by genetic and biological technology.

D. Justice and a Better Society

While the biological factors in most forms of inequality are probably slight, genetic technology does promise to create a more equal society in a very basic way: by eliminating congenital sources of illness and disability that create the most intractable forms of inequality in society. We can go to great lengths to give the ill and disabled full access to society, but their disabilities place basic limits on how equal their social participation and power can be. Our ability to ameliorate these sources of congenital inequality may even impose obligations on us to do so, at least for those who are cognitively impaired and incompetent. Admittedly, we will probably have surmounted

most disabilities through non-genetic technological fixes long before we do so through genetic therapy. But the general principle is that genetic technology promises to make it possible to give all citizens the physical and cognitive abilities for equal participation, and perhaps even to bring about a general enhancement of the abilities essential to empowered citizenship.

E. A Critical Defense

Unlike those libertarians who hold self-determination as a cardinal principle, I adopt more of a social democratic stance, and foresee legitimate limits that we can and should place on these technologies. For instance, some characteristics of society, such as social solidarity and general equality, are so important that they warrant the regulation of these technologies in the furtherance of these goals. Collective interests should also be pursued through active means, such as government subsidies for the research, development and application of genetic technologies.

Nor am I an unquestioning advocate of technological progress. Some technologies are so inscribed with harmful ends that no amount of regulation and social direction can make them worth the risk [Winner, 1986). If I were convinced that genetic technology, like nuclear weapons technology, had no redeeming qualities and only great risks, then I would embrace a complete ban.

But the potential benefits of genetic technology far outweigh the potential risks. In short, I advocate a position of critical support, a position which reflects the suspicious optimism that most people around the world have toward genetic technology.

A 1987 survey of Americans by the U.S. Office of Technology Assessment found that support for genetic engineering ranged from 84% approval for genetic modifications to "Stop children from inheriting a usually fatal genetic disease," to 44% support for "positive" genetic modification to "Improve the intelligence level and physical characteristics that children would inherit." [OTA, 1987) In a 1993 survey, more than 50% of the respondents in India and Thailand supported the use of gene therapy for the purposes of physical, intellectual or moral enhancement [Macer, 1994). A 1994 Gallup poll in the UK reports 20% of people accepting enhancement gene therapy [Nature [1994) 371: 193].

4. Arguments Against Genetic Technology

There are at least two kinds of criticisms of genetic technology, fundamentalist and non-fundamentalist. (See Mauron and Thevox [Mauron and Thevox, 1991]) for a similar distinction.) The fundamentalist or “bio-Luddite” concerns, such as those of Jeremy Rifkin, I reject fundamentally. On the other hand, I accept the validity of many of the non-fundamental concerns, but see the problems they suggest as soluble. Few of these concerns about genetic technology raise new questions for medical ethics [Proctor, 1993). The same questions have been raised by previous medical research and therapy, and those challenges have been met without bans on those technologies.

Some non-fundamentalist critics believe that, cumulatively, the risks posed by new genetic technologies are great enough to warrant postponing genetic research for some indefinite period of study and preparation. With these concerns I will argue that, with adequate technology assessment and anticipatory regulation, there will be adequate time to regulate genetic technology as we proceed; none of the risks are sufficiently weighty, individually or cumulatively, to outweigh the potential benefits.

The fundamentalist or bio-Luddite concerns I will address are:

A. Bio-Luddism 1 : Medicine Makes People Sick
B. Bio-Luddism 2 : Sacred Limits of the Natural Order
C. Bio-Luddism 3 : Technologies Serve Ruling Interests
D. Bio-Luddism 4 : The Genome is Too Complicated to Engineer

The non-fundamentalist or pragmatic concerns I will discuss are:

E. Gene Angst 1 : Fascist Applications
F. Gene Angst 2 : The Value of Genetic Diversity
G. Gene Angst 3 : The Geneticization of Life
H. Gene Angst 4 : Genetic Discrimination and Confidentiality
I. Gene Angst 5 : Systematically Bad Decisions by Parents for Children
J. Gene Angst 6 : Discrimination Against the Disabled
K. Gene Angst 7 : Unequal Access, Priority Setting and the Market
L. Gene Angst 8 : The Decline of Social Solidarity

Bio-Luddism 1 : Medicine Makes People Sick

One extreme bio-Luddite position was elaborated by Ivan Illich [Illich, 1975): medicine itself makes us sick and should be done away with. A variant on this argument is that genetic screening will eventually determine that all of us are "at risk," making everyone see themselves as sick. More troubling, genetic diagnosis might create a two-tier social system, divided between those with relatively clean genes and those with genetic disease. In other words, genetic diagnosis will make us all genetically diseased. This would be even more problematic if the genetic diagnosis was for a disease which was not yet curable.

Some medicine makes some people sicker, but I hold fast to the modernist promise that scientific progress generally improves our lives and that knowledge is better than ignorance. It is unlikely that we will ever force people to know their likelihood of developing disease, though perhaps we should educate parents and physicians to be cautious about informing children of their risks. In any case, we all know that we are at risk of dying, and with or without genetic diagnosis people view the medical history of their parents and relatives as harbingers of things to come. Both knowing and refusing to know one's genetic makeup are empowering choices for competent adults; denying people the option of making this choice does not improve their lives.

This argument also presumes just the first, screening phase of the new eugenics, and not the latter correction phase. Far from making everyone sick, the advance of genetic therapy promises to make everyone well.

Bio-Luddism 2 : Sacred Limits of the Natural Order

Rifkin has joined forces with religious leaders to assert another fundamentalist tenet, that genetic engineering transgresses sacred limits beyond which we should not "play God" [Porter, 1990). I don't believe that divine limits are discernible, and I don't believe in any "natural order" except the one we've got. As Love and Rockets point out: "you can't go against nature, 'cause when you go against nature, its part of nature too." There are no "natural limits" in our taking control of our biology or ecology. There is no "natural" way to have a baby or die. Even if there was a natural way to birth, age or die, I don't believe we are morally compelled to adopt it.

It may be that this idea of a divinely ordained biological order is distinctly Judeo-Christian-Islamic, and not shared by religions and cultures which believe in different cosmogonies. In a 1993 survey of attitudes towards genetic therapy in the Asia-Pacific region (Australia, Hong Kong, India, Israel, Japan, New Zealand, The Philippines, Russia, Singapore and Thailand) Daryl Macer reports that there was overwhelming support for genetic therapy to cure disease, and that almost no respondents were concerned that the therapy violated the natural order or God's plan [Macer, 1994).

Bio-Luddism 3 : Technologies Serve Ruling Interests

Some hesitate to argue that medical technology is bad in and of itself, but argue instead that the powerful always shape and apply technologies to further their domination of the less powerful [Hubbard and Wald, 1993]. While this is probably true, the conclusion is that all technology should be abandoned. The wealthy and powerful have more access to telephones than the poor and powerless, and telephones are used by the wealthy and powerful to collect more wealth and power. But I see the answer to be subsidized phone service and egalitarian social reform, not banning the telephone [Winner, 1986].

Bio-Luddism 4 : The Genome is Too Complicated to Engineer

A fourth fundamentalist conviction is that the genome is too complicated to engineer, and therefore there are certain to be unpleasant, unintended consequences [Glover, 1984: 33). This argument is directly parallel to the deep ecologists' conclusion that human management of the complex global eco-system is impossible, and that our only hope is to leave the planet alone to its own self-organization. Arne Naess [Naess, 1973) and Devall and Sessions [Sessions, 1980) are the modern touchstones for the deep ecological philosophy which overlaps with this biofundamentalist stupefaction in the face of evolved complexity, while movements like Earth First! take the argument to its reductio ad absurdum (AIDS is good, etc.). Outside of the anti-environmental Right, voices in defense of the possibility of eco-management have been rare [Anderson, 1987).

The genome and eco-system are both very complicated, and the ability to do more than correct local defects in either may be many decades away. But eventually we will have the capacity to write genetic code and re-engineer eco-systems, and to computer-model the structural consequences of our interventions on future bodies and planets. Of course, it will be difficult to decide when the consequences of a genetic blueprint are sufficiently well-understood that it is safe for use, and our current regulatory scheme is probably not yet adequate to the task [Zallen, 1989; Ledley, et al., 1992; Ledley, 1991; Areen and King, 1990; Council for Responsible Genetics, 1993).

Our understanding of the genome and ability to predict consequences must be very robust before we allow human applications or the release of animal applications. While Elias and Annas [Elias and Naess, 1992) object to "positive" germ-line therapy, which I would defend, they propose two sensible preconditions on the application of gene-engineering:

> (a) that there should be considerable prior experience with human somatic cell gene therapy, which has clearly established its safety and efficacy; and
>
> (b) that there should be reasonable scientific evidence using appropriate animal models that germ-line gene therapy will cure or prevent the disease in question and not cause any harm, and
>
> (c) all applications should be approved by the NIH's Working Group on Gene Therapy and local Institutional Review Boards, with prior public discussion.

Again. I also endorse the formulation of the Preliminary Draft of a Universal Declaration on the Human Genome and Human Rights [UNESCO International Bioethics Committee, 1995) which states that

> 7. No intervention affecting an individual's genome may be undertaken, whether for scientific, therapeutic or diagnostic purposes, without rigorous and prior assessment of risks and benefits pertaining thereto...

Those of us who believe in the possibility of effective public regulation may differ widely as to the appropriate standards the public and these regulatory bodies may use. But liberals and conservatives differ fundamentally from those bio-Luddites who believe that the natural world is so complicated, and governments so unwise, that all intervention must be forbidden.

Undoubtedly, genetic design will undergo extensive experimentation in the design of animals before any human experimentation begins, and I see few ethical problems with using animals for experiments in genetic design. The problem with animal research is that it might produce species that are dangerous if released into the eco-system. Release of gene-engineered creatures should be done very cautiously, and it may be that we should have a moratoria on the release of genetically engineered plants and animals until we have adequate oversight [Council for Responsible Genetics, 1993). Genengineered micro-organisms are a much greater risk than genengineered humans, since humans don’t breed rapidly, are completely vulnerable for years of childhood, are large and visible, and can be controlled with firearms.

The next step will be to decide when genetic products can be applied by adults to themselves, for therapeutic or other reasons. It is possible to imagine social risks from self-applied genetic modification, and we would probably require genetic products to go through the same Food and Drug Administration testing that pharmaceuticals go through. On the other hand, I am in favor of substantial liberalization of our drug and pharmaceutical regulations, including the legalization of narcotics and psychotropic drugs, and I am also for a fairly liberal policy towards genetic self-modification.

The real dilemma with testing comes with the genetic design of children [Fletcher, 1985). Even if we had an extreme market society which permitted unregulated genetic modification of eggs, sperm and embryos, I suspect that few women would risk bearing and raising children whose "product safety" had not been guaranteed. Nonetheless we will inevitably continue to strictly regulate the genetic modification of children. The safety and efficacy of genetic products will not only be demanded by parents, but also by federal agencies and providers.

While daunting, these are many of the same issues raised by drugs and medical devices today. With or without genetic design products we are moving to a new phase of technological assessment of medical products balancing the demands for demonstrated efficacy and safety with demands for rapid release of useful therapies, and the individual freedom to control one's body. Genetic products will be only one of the ultimately soluble challenges our regulatory scheme will face.

Gene Angst 1 : Fascist Applications

Another concern expressed by many critics of genetic technology is the dire consequences of the re-emergence of fascist, racist and authoritarian regimes, and their use of genengineering to produce compliant, genetically uniform subjects. The first point to make about fascist uses of eugenic ideology or technology is that nothing a democratic society does to forbid itself genetic technology will have any impact on future or contemporary fascist regimes. Indeed, if there is any "national security" to be gained from genetic technology then it would behoove liberal democracies to gain them as well. For instance, public health campaigns to detect and correct the genetic predisposition to alcoholism, or to enhance the intelligence of children, could make nations much more powerful and productive than their more conservative neighbors; would it not be in the interest of democracy itself for democracies to pursue these measures?

Yet, what if the fascist regimes found strength in breeding different castes a la *Brave New World,* and democracies could only meet the challenge by becoming equally repugnant? This is a possibility, and it raises the important point: the way to stop fascist uses of genetics is to prevent the rise of fascism, not to restrict the emergence of genetic technology. As we see today with Iraq and North Korea, firm agreements by right-thinking nations that only the United States is sufficiently moral to be allowed the ownership of nuclear and chemical weapons has little impact on recalcitrant regimes. If we cannot effectively prevent the proliferation of nuclear technology, with its large radioactive facilities visible to satellites, we will have even less success with genetic laboratories. I support the strengthening of the legal, judicial and military might of U.N.

so that it might begin to enforce global law, but I think the proper task for such a New World Order is the suppression of fascist regimes likely to use genetics for nefarious ends, not the policing and suppression of outlawed genetic technologies. Bonnicksen [Bonnicksen, 1994A) has written a very complete review of the global efforts to harmonize national policies towards genetics; the responses to her piece [Cook-Deegan, 1994; Blank, 1994; Chadwick, 1994; Fletcher, 1994; Knoppers and Bris, 1994; Mauron, 1994; Shapiro, 1994; Wertz, 1994; Winston, 1994; Byk, 1994; Kielsten, 1994; Macer, 1994; Bonnicksen, 1994B) are also fascinating in that they generally suggest a softening of the bioethics community toward germ-line therapy, if not enhancement.

Genetic science does not itself encourage racism or authoritarianism. In fact, the advance of scientific knowledge may even erode the pseudo-scientific basis on which most eugenics has rested. Presumably the advance of genetic science will tell us whether there is a genetic basis for gender and racial differences in abilities, or not, and how important these are. If there are genetic factors in gender or racial difference, they will most likely be revealed as minor beside the social factors, and the genetic factors will become ameliorable through a technical fix. Some insist that knowledge itself, or knowledge about forbidden topics, will lead to fascism; I prefer the modernist optimism that knowledge is at least neutral towards, and sometimes a scourge of, obscurantism.

Gene Angst 2 : The Value of Genetic Diversity

Another concern that is often expressed vis-à-vis genetic engineering is the alleged aesthetic or biological virtues of genetic diversity. Many refer to the evidence from ecology that ecosystems are more stable when they contain a greater diversity of gene-lines. Some suggest, for instance, that our very survival as a species might hinge on genetic diversity if we faced some blight that only a few were resistant to.

The first objection to this argument is that diversity is not a sufficiently compelling ethical or aesthetic virtue that it can trump the prevention of disease, or the improvement of the quality of our lives. We "reduced diversity" when we eradicated smallpox and polio, with no regrets. We "reduce diversity" when we insist on compulsory education because we don't value the diversity of extreme class inequality.

The second objection to the diversity argument is that any loss of adaptiveness through biological diversity will be compensated for by an increase in biological knowledge and control. It is unlikely that a future society would have the ability to create "superior genes" and yet be unable to meet the challenge of infectious disease.

Third, the regime of genetics I have outlined is a liberal one, which should produce as much diversity as it reduces. While I support public provision of genetic screening for disease, I oppose any eugenic coercion. People desire different attributes and abilities, for themselves and their children; for every Aryan parent that chooses a blond, blue-eyed Barbie phenotype, I expect there would be a Chinese parent choosing a classic Chinese ideal of beauty. True, this might lead to the convergence toward a few physical and mental ideals, though I suspect that phenotypic fashions will change quickly. But I see no

ethical difference between permitting people to change their genes in conformity with social fashions, and permitting them to change their clothes, makeup and beliefs to do so.

Perhaps there is some aesthetic or civic virtue in phenotypic diversity. If it is valued by the public, let us establish incentives for diversity. If the number of parents choosing to raise blond boys is offensive to public opinion, we can give tax incentives for parents who bear dark-haired girls. In any case, we will quickly know if there are broad trends that we find offensive, and I trust our ability to craft non-coercive policy responses to re-establish any *valued* diversity we feel may be eroding.

Gene Angst 3 : The Geneticization of Life

A more diffuse "cultural" concern about genetic technology is that people will begin to see genetics as more central and influential in life than they should. For instance, Richard Shweder [Shweder, 1994) believes that eugenics and genetic determinism are being fueled by contemporary genetic technology and research, at the expense of attempts to ameliorate social ills. Other critics, such as Barbara Katz Rothman [Rothman, 1989), see genetic technology as contributing to the reification of the genetic ties between people at the expense of valuing their social relationships.

Both of these concerns have some legitimacy. Undoubtedly the public will invest genetics with more importance in the production of disease, intelligence and other characteristics than will be warranted by a more balanced scientific perspective. And as the current market for in vitro fertilization shows, people will pay astronomic sums for the chance at a genetic tie to their children, when they would have otherwise had to adapt to adoption in an earlier age.

Is the misapprehension of genetic influence, and disproportionate concern with genetic ties made more or less likely by the advance of genetic technology? When we begin screening for the genes which make lung cancer more likely, it won't take long for the "negatives" to understand that they are still at risk from smoking or asbestos. As genetic diagnosis and treatment become more prevalent people will become as sophisticated about their genetic diagnoses as they are about the risks of cigarette smoking or cholesterol: risk-averse folks will take their genetic propensities very seriously, and risk-prone folks won't. If they lack an OB gene, and yet get fat, they will redouble their dieting.

Parents will probably be less gene-obsessed when they can either have a child with all their parents' genetic flaws, or one that shares their facial features, but has been tweaked with someone else's good teeth, arched feet, height, and intelligence. It will considered obsessive and dumb to give your kids only parental genes, and parenting will be the definition of parental ties, not parentage.

As to Rothman's concern over the primacy of social ties, fertility treatments, surrogacy and genetic technology do not *reify* the genetic bond, but cause its slow *deconstruction* [Macklin, 1991; Stanworth, 1988). Just as heart-lung machines forced us to confront the separability of heart and brain death, genetic intervention will force us to clarify the relationship of social ties and genetic ties. If you've picked most of your child's

genes from a catalog, its likely to reinforce the importance of your social parenting ties to your children.

Our ability to control genetics will help to clarify the appropriate weight to give to genetics in culture and social affairs. As the nature-nurture relationship becomes clarified, people will not be any less likely, probably more likely, to fix the nurture side of their problems. What if some future polity determined that it would be easier to genetically engineer resistance to smog than to clean up industrial air pollution? It would be a tragedy, but not really that different from our struggles over toxics today, which we compensate for through health care expenditures. Genetic technology won't make it any less likely that we will have an ecologically sane, healthy or equal society, only that our fall-back options will be more effective.

Gene Angst 4 : Genetic Discrimination and Confidentiality

Many opponents of genetic investigation are concerned that growing genetic knowledge will lead to discrimination against the "genetically diseased and disabled." Some assert that genetic therapy itself will increase this discrimination by bringing intense pressure to bear on those with genetic diseases to have the disease corrected, and not burden society and future generations with their diseases.

It is certainly true that employers are already attempting to discover the genetic risks of their employees, and deny employment or health insurance on the basis of this risk profile. A bill guaranteeing the confidentiality of genetic information has been introduced in the U.S. Congress, and while it has not yet passed, some form of confidentiality is certain to be guaranteed by the turn of the millennium. In addition, the Americans with Disabilities Act and similar legislation in the U.S. will clearly be mustered to defend workers from genetic discrimination. The U.S. Human Genome Project's Task Force on Genetic Information and Insurance has recommended that genetic screening be accompanied by universal access to insurance, and that genetic screening not be used to deny insurance [Murray, 1993). Internationally, there is also a consensus on these reforms, expressed for instance in the Preliminary Draft of a Universal Declaration on the Human Genome and Human Rights [UNESCO International Bioethics Committee. 1995) which states that

> 8. No one may be subjected to discrimination on the basis of genetic characteristics and that aims or has the effect of injuring the recognition of human dignity or the enjoyment of his or her rights on the grounds of equality.
>
> 9. The confidentiality of genetic data associated with a named person and stored or processed for the purposes of research or any other purpose, must be protected from third parties.

Keeping genetic information confidential from insurers and other non-medical personnel in the health care system is trickier, since the records will show any special screening or treatment that genetic risks called for. Unregulated, the use of genetic risk information could greatly strengthen the ability of insurers to exclude the illness-prone from their risk pools, or charge them premiums equivalent to the costs of their potential treatments. Again however, popular insurance reform legislation before the U.S. Congress will ban "risk-rating" and excluding clients with "pre-existing conditions."

These two reforms will likely reduce the number of insurance companies in the country by half or more, and make genetic discrimination in health insurance a more or less moot point. Some have suggested further that the pervasiveness of genetic information will make private health insurance impossible; to which I say, good riddance.

There are undoubtedly many other nefarious uses to which knowledge of someone's genetic make-up can be put. But genetic information is only one small category of the information about our lives which is potentially in the public domain, and potentially injurious. The regulation of genetic technology really has very little to do with whether we establish data privacy in the 21st century.

Gene Angst 5 : Systematically Bad Decisions by Parents for Children

The right to a "custom-made child" is merely the natural extension of our current discourse of reproductive rights. I see no virtue in the role of chance in conception, and great virtue in expanding choice. To reiterate my starting points, embryos and fetuses are biological property and parents should be allowed to modify or terminate them as they see fit, within broad social constraints. If women are to be allowed the "reproductive right" or "choice" to choose the father of their child, with his attendant characteristics, then they should be allowed the right to choose the characteristics from a catalog.

What then are the broad social limits to be placed on parents genetic decisions? It is obvious that our polity can and should place limits on the genetic decisions parents make. Glover [Glover, 1984) asks, for instance, what if a religious minority were to engineer a sign of their faith on their children's foreheads, and engineer their brains to be incapable of reading in order to prevent apostasy? Certainly I would accept an intervention against parents who wanted to systematically deprive their children of abilities, though I am not so certain about the religious symbol.

Or take the case of sex selection, which has been a very sore point for pro-choice bioethics. While we may find gender-biased parents distasteful, it clearly preferable that parents have *wanted* children rather than *unwanted* children, and it is their right to decide what they want. It should also be a goal of public policy to discourage infanticide, even if the result is an increase in abortions, and to make abortion unnecessary by increasingly the availability of preconceptual choice. Potential women are not women, and so they have no standing in a claim that parental preferences violate their rights.

Sex selection becomes a matter of public concern if parents' decisions cumulate to undesirable outcomes, such as sex imbalanced populations. There is ample evidence that prenatal diagnosis in China and India [Kusum, 1993) leads to almost exclusive abortion of female fetuses. It still isn't obvious to me what the problem is with sex imbalance in the population. The supposition that fewer women in the next generation reduces the power of women as a demographic group may be true, though rather simplistic, and not yet a compelling reason for taking away the reproductive liberty of this generation of women. Fewer women will reduce the population growth rate, which is probably a welcome outcome, though two sexes will soon be as unnecessary for reproduction as they are for parenting. Men may find it harder to find brides, and be forced to consider the

virtues of celibacy, masturbation, polygyny and homosexuality, which again should be no concern of the State.

In any case, if there was a public gnashing of teeth and tearing of hair at the emerging sex imbalance in baby population, we'd have several years to think about policy responses. As I suggested above, my preference would be financial incentives to pursue other choices, rather than coercion. The point is that we would have ample opportunity to confront these challenges as we proceed, and need not impose hasty preemptive bans.

Gene Angst 6 : Discrimination Against the Disabled

Opponents of sex selection and of eugenic efforts against genetic disease argue that these decisions are acts of prejudice against women and the disabled, and perpetuate the second class status of women and the disabled by focusing on genetic rather than social amelioration. In the first place, embryos and fetuses are not persons, and therefore their rights cannot be violated as persons or as members of oppressed social groups. While parents may make reproductive decisions for many reasons we disapprove of, such as aborting a fetus because the father was accidentally of the "wrong" race, this is not a reason to intervene.

The alleged link between choosing to abort a disabled child, or correcting their disability through genetic therapy, and the perpetuation of oppression of the disabled seems tenuous at best. Perhaps by reducing the population of disabled we reduce their power at the ballot box. But a parent's moral obligation to give their children the greatest quality of life, and the fullest range of abilities, includes not only the obligation to treat a disabled child with respect and love, but also the obligation to keep them from having disabilities in the first place. It also seems likely that a society with fewer disabled would increase rather than decrease their per capita expenditures on the disabled.

Gene Angst 7 : Unequal Access, Priority Setting and the Market

As a social democrat, one of my gravest concerns is how social inequality will constrain access to genetic technology, and how genetic technology may reinforce social inequality. Establishing the appropriate balance of state and market in genetics starts with the creation of a national health budget, most likely through the creation of a national health system, such as the Clinton plan or some other form of national health insurance. Such a system allows the ethical determination of utility trade-offs, from what the level of health care expenditures should be, to what should be included in the basic package of guaranteed medical services and what should be consigned to the private medical market. I believe the Oregon experiment in public, accountable, utility-theory-based rationing is the model for this kind of priority allocation. The Clinton administration's plan for health care reform would also have established a minimum universal package of health benefits, and permitted plans to compete onthe basis of additional services.

If we had such a system, I don't think most fertility treatments would make the cut into the minimum universal package. Future positive genetic "enhancements" would not

be included until safety, efficacy and voluntariness was adequately assured. On the other hand, genetic screening and corrective genetic therapy would clearly be socially acceptable, cost-effective, and therefore a plausible positive right. This leaves me in a quandary – I want reproductive technologies and genetic therapies to be legal and available to all who want them regardless of income, but I'm not prepared to argue that they are a positive right worthy of public subsidy. Yet, if gene products are left in the market, only the wealthy will have access to them, with the upper-classes having more life opportunities and potentially becoming genetically healthier and more intelligent than the poor, which is unethical in an equal opportunity society [Daniels, 1986).

These problems are really a sub-category of the larger task of determining which medical tests and procedures should be:

- required by law, e.g. vaccinations
- publicly funded, but not obligatory, e.g. abortion in progressive states
- encouraged, but unsubsidized, e.g. exercise
- discouraged, but not banned, e.g. smoking
- banned., e.g. heroin

Any assignment of genetic technologies to the categories between obligatory and forbidden allows for potential inequality. Most opponents of genetic technology, when pressed, would stop short of banning these technologies out-right, and thus leave them to be inequitably distributed by the market. At the other extreme, outside of science fiction [Wagar, 1989), there are no audible voices calling for a program of mandatory, universal genetic redesign. This leaves me with Glover in the usual social democratic, mixed-market middle: try a little public, and a little private, and we will tinker with it as we proceed.

A parallel, and very intriguing, question is whether, when, and by whom genetic products may be owned, patented and profited from. Genetically designed animals began to be patented in 1987. The U.S. Congress has rejected the patentability of human beings, but the Patent Office has accepted the principle that parts of the human genome may be patented once their functions have been determined. The Bush administration's NIH attempted to protect future commercial and scientific research by patenting stretches of DNA which had been decoded, but whose function had not been identified, raising the additional question of what the proper role is for public property in genetics. American Human Genome Project scientists have entered into lucrative commercial biotechnology ventures, profiting from their publicly-funded research [Fisher, 1994). Again, the social democratic muddle is that there must be sufficient protection of genetic products encourage innovation, while at the same time there must also be a strong presumption in favor of public ownership of genetic code and medical knowledge as the common property of humanity.

Fishman's [Fishman, 1993) article "Patenting Sub-Human Beings..." provides a detailed discussion of the current status of animal and human genetic patents in U.S. Constitutional law, and the confused future status of intermediate transgenic species. She proposes an amendment to the Patent Act defining "human being" as either a being possessing one of a number of higher cognitive faculties not yet found in other primates, or the progeny of a human mother and human father. I believe the former formula is the

direction to go; the current debates over anencephaly and severely disabled newborns suggest to me that not all human progeny are, or should be, accorded "humanity," if humanity means a "right to life." Attempting to determine the cognitive faculties of different forms of life, human, non-human and intermediate, and allocating rights according to these faculties suggests the possibility of a general decision-rule free of (human) racial prejudice.

Gene Angst 8 : The Decline of Social Solidarity

Finally some critics suggest that parents would become alienated from their genetically engineered children. Dator [Dator, 1989) and other post-humanists suggest that genetic engineering and other technologies may create conflict between humans and post-humans, and threaten social solidarity. I think this is a serious concern, and one goal of the social regulation of genetic technology would be to moderate the rapidity with which society genetically advances and diversifies. The gaps between the bodies and abilities of parents and children should not be so great as to make parenting impossible. Also the unenhanced public's concerns will inevitably be a factor in regulating the enhancement of the modified minorities. While some of these conservative concerns may be warranted, if the enhanced feel they have no responsibility to the unenhanced and seek to dominate or exploit them, we must also avoid allowing simple chauvinism and fear of the unknown to stop genetic enhancement.

While tremendous social conflicts can be imagined, they are not that different from the conflicts between ethnic minorities and majorities, or between the First World and the Third, or between social classes. Like other sources of social division, the relations between new genetic communities will hopefully be mediated by the same institutions, courts and legislatures, minority rights and majority rule. The real challenge faced by a post-human ethic is to define new parameters for which forms of life should be considered property, social wards (neither property nor competent persons, such as children), and persons with full citizenship.

5. Conclusion

In the midst of a current health care debate, with ethicists and humanists urging us to embrace financial and existential limits, and give up the quixotic quest for immortality, the post-humanists say "Some alive today may never die." The potential problems created by new medical technology are numerous, and we must work hard to ensure that our societies are such that they create more good than harm. But I believe this an achievable goal, and that genetic technology offers, if not immortality, such good that the risks are dwarfed. Like all speculation (and all utilitarian judgments are based on social speculation) this optimism is founded on numerous points of faith. But I find faith in the potential unlimited improvability of human nature and expansion of human powers far more satisfying than a resignation to our current limits.

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